Madison Bell

Community-Based Program Proposal

Background

Cerebral palsy (CP) is a very common neurological disorder that causes motor disability that manifests in deficits such as developmental delays, abnormal movement patterns, contractures, spasticity, bony deformities, abnormal gait, decreased strength, impaired sensation, and decreased endurance.[1] This presentation then leads to decreased activity and participation levels and increased sedentary behavior, and thus the development of secondary chronic conditions such as obesity, chronic pain, cardiovascular disease, and osteoporosis.[2-3] The health promotion program presented here will be tailored for children with CP by aiming to encourage regular physical activity, provide nutritional advice, as well as increase social interaction with peers. This introduction will dive into the evidence of how a program that encourages exercise and adequate nutrition can be successful in increasing one's overall functional mobility and quality of life while simultaneously decreasing the risk of developing secondary chronic conditions.

Due to the associated risks of increased sedentary behavior in children with CP (higher blood pressure, obesity, development of cardiovascular disease[4-5]), extensive research has been done to assess the ability of regular physical activity to mitigate these risks. Evidence-based physical activity guidelines have been created specifically for children with CP that have demonstrated significant positive results by individualizing exercise parameters (frequency, intensity, time, type of activity) to each child for both cardiorespiratory and resistance exercises.[6] A systematic review of randomized control trials (RCTs) found that participation in aerobic exercises led to improvements in

cardiorespiratory endurance (measured via arm cycle test or shuttle run test) and participation in lower extremity strength training led to increased strength and function in those with CP.[6] These results provide a clear indication that children with CP can in fact benefit from participation in exercise. This program will be sure to incorporate vigorous activity (running, jumping, skipping, etc) as this is beneficial for reducing development of future cardiometabolic complications in children with CP.[4] Additionally, participation in regular physical activity can help to decrease the risk of developing obesity and thus other secondary conditions such as cardiovascular disease.[2] A community-based program that utilized specific exercises that focused on strength (upper extremity, lower extremity, and core) and balance training also demonstrated functional strength and balance improvements in children with CP.[7] This is excellent evidence to use to demonstrate the potential effectiveness of this health promotion program.[7] Additionally, providing education on energy conservation techniques for completion of exercises has shown to be a successful tool for capitalizing on the benefits of cardiorespiratory exercise.[3] Implementation of community physical activity as presented with this health promotion program can also have positive effects for increased social interaction and overall mental health.[3]

Providing adequate nutritional advice is also imperative for maximizing the effects of exercise, mitigating the development of secondary conditions, and minimizing the risk of malnourishment.[3] Specifically, parents of children with CP who are educated on and utilize appropriate levels of calcium and vitamin D supplements can help decrease the child's risk of developing osteopenia and secondary fractures that could occur with increased activity levels.[3] Poorer nutrition is associated with more doctor

visits and more hospitalizations and therefore decreased participation at home, in the school, and in the environment, and can be addressed with adequate education and nutritional advice by a nutritionist or dietitian.[8] Nutritional advice for caregivers of those with children with CP can help improve the child's overall general health, social participation, brain growth, and bone health while also preventing development of decreased bone mineral density (if undernourished), diabetes, or cardiovascular disease.[9] Additionally, improving nutrition and feeding habits can help increase social interaction by decreasing the potential associated embarrassment that comes with eating with peers.[8]

Using a health behavior change model such as the social cognitive theory to implement these interventions will be important for assessing the child's cognitive and environmental factors that influence their behavior such as self-efficacy, education level (of caregiver too), learning style, social support, and barriers and opportunities to implementing health behavior change into their lifestyle.[10] By addressing these factors for each individual, intervention can be tailored and specific to create a holistic and longer-lasting approach to lifestyle intervention.[10] Specifically, using social cognitive theory as the framework for implementation of regular physical activity can be effective, and self-efficacy and goal-setting are the two most influential constructs to address with individuals.[11] By increasing the child's (and caregiver's) level of self-efficacy, they will be more motivated to reach their goals. Additionally, using the family systems theory to help guide intervention by encouraging active caregiver participation in their child's overall health is helpful for increasing the family's overall quality of life.[12] Establishing rapport and providing education respectfully can help empower the caregivers to make

educated health decisions for their child and encourage physical and psychological growth.[12]

Using the social ecological model for identifying and addressing health behaviors is also important for encouraging long-term change.[13] At the individual level, it will be important to assess the child's (and caregiver's) motivation and attitude towards participating in regular physical activity and maintaining adequate nutrition in order to best meet the child at their level and tailor interventions specific to what they enjoy.[13] At the interpersonal level, it will be imperative to gauge the child's social support with family and caregivers and include them in this lifestyle change in order to see the best results.[13] A study assessing the effectiveness of using the social ecological model for promoting physical activity found that individual and interpersonal factors have the most influence on participation in moderate-to-vigorous physical activity and should thus always be discussed in order to encourage maintenance of change in the health behavior.[14]

Outcome measures that will be helpful to use to track the individual's changes in function, strength, and endurance include the Gillette Functional Ability Questionnaire (FAQ), 5x Sit-to-stand (5xSTS), and the 6 minute-walk-test (6MWT). The FAQ is a reliable and valid scale that will help encourage the family-centered approach to care as discussed previously by assessing the level of locomotor ability the caregiver thinks the child is at.[15] This will help monitor the caregiver's perception of their child's level of functional mobility over time as well as provide goals and interventions accordingly for activities where the child may need to work on such as jumping, hopping, riding a bike, and ball skills.[15] The 5xSTS is a reliable assessment to gather a quick measure of the

child's functional lower extremity strength and has been validated specifically for children with CP.[16] There has also been an established minimal detectable difference (0.06 rep/s) to help form functional strength goals.[16] Since the program will be incorporating cardiorespiratory activities as well, it will be important to measure the child's level of cardiovascular endurance via the 1, 2, or 6 MWT (depending on the child's baseline) and assess changes accordingly (minimally clinically detectable change of 34.4 meters for the 6MWT).[17,18] Additionally, while there is not an outcome measure specifically for tracking nutritional changes that will be used, it will be important to check in regularly with the caregiver and assess the child's nutritional intake via self-report and encourage the caregiver to use a nutrition diary to make this an easier assessment.

The sufficient evidence presented here will be the foundation for implementing health behavior change with this health promotion program. By educating and encouraging regular physical activity, social participation, and adequate nutrition, this program could help mitigate the development of secondary chronic conditions while also decreasing overall healthcare costs and the burden that comes with having to schedule visits with multiple providers for children with CP.[3, 8]

Program Goals

1. In 12 weeks, participants will demonstrate an improvement of 34.4 meters on the 6MWT according to the minimally clinically detectable change to demonstrate improved endurance that will help translate to improved participation in playtime with peers.[18]

2. In 12 weeks, participants will demonstrate an improvement of 0.06 reps/second on the 5xSTS test according to the minimal detectable change for children with CP to demonstrate improved lower extremity strength and function.[16]
3. In 12 weeks, caregivers of participants will demonstrate an improvement of 2 points on the FAQ according to the minimally clinically detectable change to demonstrate improvement of the child's level of functional mobility according to the caregiver's perception.[19]
4. In 12 weeks, caregivers and participants will demonstrate adherence to use of a nutrition diary 5-7 days/week to demonstrate improved ability to track nutritional intake independently and enhanced awareness of nutritional habits.
5. In 12 weeks, participants will demonstrate adherence to exercise recommendations outside of the program 90% of the time to demonstrate independence with ability to maximize health benefits from physical activity.

Methods

Who

This program will be offered to any child age 2-18 years-old with ambulatory CP who is able to safely attend. There will be at least 4 physical therapists (PTs) and 2 occupational therapists (OTs) present at each weekly group session. One dietitian or nutritionist will be present at each initial assessment, 4-week follow-up, and final assessment visit. In order to maintain appropriate levels of supervision and instruction, there will be a ratio of 1 therapist to 5 participants at all group sessions, indicative of a total of 30 participants total per session. For recruitment, e-mails will be sent out to the PTs in the schools in eastern Wake County as well as local pediatric PT clinics for

therapists to keep in mind for their eligible patients. Enrollment will start with an initial one-hour one-on-one assessment via a therapist to determine if the child will benefit from the program based on ambulatory status, goals, baseline function, ability to attend weekly sessions, and ability to complete recommended additional exercise outside of the program. If deemed fit, enrollment will occur until the program reaches capacity and continue as participants are discharged over time. If there is an overwhelming number of participants eligible for participation, more therapists and/or more sessions will be added as needed.

The therapists will have adequate knowledge with their training background on how to complete an appropriate evaluation of participants and how to tailor and progress interventions accordingly throughout the program. Groups within each session will be divided according to their baseline level of function as determined with the outcome measures discussed previously at the initial assessment. Follow-up assessments using the same measures will occur after 4 weeks of participation in the program and again at completion of the program. All assessments and interventions will be administered by a trained therapist. To recruit therapists and dietitians, word-of-mouth and e-mails to various pediatric clinics (physician, OT, PT) will be used throughout eastern Wake County to encourage community involvement.

What

This program will focus on using evidence-based exercise parameters specific to children with CP at each group session as well as providing nutritional advice at the initial, 4-week follow-up, and final visits. The sessions that include the caregiver meeting with the dietitian will consist of reviewing the child's nutrition diary and offering

appropriate recommendations and changes accordingly. The exercise interventions will include functional activities that will incorporate both strengthening and aerobic components. Exercises will be individualized to each subgroup based on baseline level of function. Examples of activities that will be incorporated into fun and interactive games include running, jumping, hopping, skipping, obstacle courses, sit-to-stands, and more. Participants will each be given a handout at the beginning of the program that provides the recommendations for parameters for participation in additional exercise outside of this program to maximize benefits. Since the participant will only be coming into the program once a week, it will be recommended to them and their caregivers that they participate in aerobic exercise 1-2 more times per week and strength training 2-3 more times per week. The exercise prescription guidelines that will be used during the program sessions and recommended to the caregivers and participants for use outside of the program are as follows[6]:

Table III: Recommendations for exercise and physical activity prescription among people with cerebral palsy

	Recommendation
Exercise	
Cardiorespiratory (aerobic) exercise	
Frequency	Start with 1–2 sessions a week and gradually progress to three sessions a week
Intensity	>60% of peak heart rate, or >40% of the heart rate reserve, or between 46% and 90% VO_{2peak}
Time	A minimum time of 20min per session, and for at least 8 or 16 consecutive weeks, depending on frequency (2 or 3 times a week).
Type	Regular, purposeful exercise that involves major muscle groups and is continuous and rhythmic in nature
Resistance exercise	
Frequency	2–4 times a week on non-consecutive days
Intensity	1–3 sets of 6–15 repetitions of 50%–85% repetition maximum
Time	No specific duration of training has been identified for effectiveness. Training period should last at least 12–16 consecutive weeks
Type	Progression in mode from primarily single-joint, machine-based resistance exercises to machine plus free-weight, multi-joint (and closed-kinetic chain) resistance exercises. Single-joint resistance training may be more effective for very weak muscles or for children, adolescents or adults who tend to compensate when performing multi-joint exercises, or at the beginning of the training
Daily physical activity	
Physical activity (moderate to vigorous)	
Frequency	≥5d/wk
Intensity	Moderate-to-vigorous physical activity
Time	60min
Type	A variety of activities
Physical activity (sedentary)	
Frequency	7d/wk
Intensity	Sedentary (<1.5 METs)
Time	<2h/d or break up sitting for 2min every 30–60min
Type	Non-occupational, leisure-time sedentary activities such as watching television, using a computer, and/or playing video games

METs, metabolic equivalent of tasks.

Each group session will start with a 5-10 minute warm-up (walking, gentle mobility drills) followed by 20 minutes of aerobic activity (running, jumping, jump rope, dancing, various sports), 20 minutes of strength training (step-ups, sit-to-stands, push-ups, sit-ups, etc.), and a 5-10 minute cool-down of similar activities as the warm-up. Specific exercises will be individualized and varied from session to session to increase

engagement and variety. Exercises will be progressed by adding resistance or challenging balance with completion. Gym equipment needed includes chairs, jump ropes, free weights, foam pads, various objects to create an obstacle course, a stereo/speaker, and an accessible open area to allow room to run and play.

The interventions used in this program will aim to address multiple levels of the social ecological model (SEM) and associated barriers to encourage long-term change.[13] By tailoring intervention progressions to each participant as well as providing education on appropriate levels of exercise and nutritional habits, this addresses the individual level of the SEM and the associated barrier of lack of knowledge of the benefits of these interventions.[13] Additionally, the interpersonal level of the SEM will be addressed by continuously engaging with the child's caregiver throughout the program and encouraging an active role of the child's social support system in their lifestyle and behavioral changes.[13] By discussing perceived barriers with the participant and their caregivers at the individual and interpersonal levels at the initial assessment, this program can help address such and encourage long-term change.[13] Additionally, the social cognitive theory will be used for the basis of implementation of education by assessing the participant's levels of self-efficacy, education level (of caregiver too), learning style, social support, and barriers and opportunities to implementing health behavior change in order to create a holistic and individualized treatment approach.[10] Goal-setting with the participant and the caregiver is an important construct of the social cognitive theory framework that will be used at the initial visit and re-assessed throughout the program.[11]

<u>When</u>

This program will occur from 6pm-7pm initially only on Mondays, but an additional night may be added depending on availability of therapists and number of eligible and interested participants. The recommended duration of the program will be once/week for 12 weeks but can be shortened or lengthened depending on progress made and whether or not there is a waitlist of participants that will get priority for enrollment before participants that are re-enrolling. The program will continue to meet throughout the year accepting new participants accordingly. Due to this being a volunteer program for the therapists on top of their jobs, the participants will only be meeting once a week. This creates the need to further emphasize the educational component of this program focusing on the importance of participating in the exercise recommended in the handout outside of the program to maximize potential benefits.

Where

This program will occur in the Knightdale Recreation Center gym that will be reserved for this class on Monday nights.[20] Initial assessments will also be completed at the Knightdale Recreation Center, but in a reserved office room.[20] The Town of Knightdale has expressed interest in expanding their hosting of community-based programs and is looking forward to partnering with this program. To further address SEM barriers such as lack of access to facilities or lack of finances, the cost of this program will be covered by sponsors in the eastern Wake County community.

How

Recruitment details for both participants and therapists discussed previously (refer to subtitle “Who”). If a potential participant is interested, they will follow-up via the e-mail provided on the flyer to determine eligibility. The lead therapist will ask questions

via e-mail to determine the participant's ambulatory status, specific activity goals, ability to attend weekly sessions, and ability to complete recommended additional exercise outside of the program. If deemed eligible, a one-hour initial assessment visit will be scheduled in-person according to the therapist and participant's schedules. The initial assessment will start with obtaining a subjective history from the caregiver (and participant if applicable) about their current activity level and nutritional status. Objective measures performed will include general strength and ROM, the 6MWT, the 5xSTS, and the FAQ. Equipment needed will include a chair, stopwatch, pen and paper, goniometer, and measuring wheel. These same assessments will be revisited after 4 weeks and at the end of the program at 12 weeks to document change according to minimal detectable differences discussed previously. Additionally, education will be provided verbally and through a handout on the recommendations for exercise to be completed outside of the program and its importance to the longevity of benefits. Participants and their caregivers will also be asked to keep a daily nutrition diary and discuss the entries with the nutritionist at the same time points to address any challenges and changes accordingly.

Program Evaluation

At the end of the program, the scores from the outcome measures will be compared to the initial scores to see if a detectable change has occurred over the course of the 12 weeks to demonstrate improved functional mobility. Specifically, there will hopefully be improvements of at least 0.06 reps/second for the 5xSTS, 34.4 meters for the 6MWT, and 2 points for the FAQ. Additionally, there will be discussion about if the child is meeting the exercise recommendations outside of the program and their

current nutritional habits. Goals of the program and goals of the individual will be re-assessed to determine if they have been met and how to move forward if not. If goals were met, it can be stated that the child has made functional strength and endurance gains as well as increases in self-efficacy and ability to use the education they have been provided.

A survey will also be provided to the caregiver (and participant if age and cognition level is appropriate) at the end of the 12 weeks about their perception of the quality of the program, its effectiveness, and their satisfaction or lack thereof. Questions will address factors such as ease of access, if the time slot was appropriate and convenient, if the child enjoyed participating, if the child felt safe, if they felt they were able to increase their social skills with other children, if the caregiver is likely to recommend this program, if the child's quality of life has improved, and overall satisfaction with effectiveness of the program. This will provide ongoing data about factors of the program that should remain the same or should change and provide insight of its strengths and weaknesses to address accordingly. Additionally, in order to stay up to date with the program goals that align with pertinent outcomes of participants accordingly, the director and assistant director of the program should meet to re-evaluate the program's mission and goals 1-2 times/year.

In order to ensure adequate utility and quality of the program, there should also be an evaluation completed by the directors and therapists using the the Center for Disease Control framework.[21] The creation of this evaluation will include assessment of how the program is engaging the stakeholders, using evidence for interventions, justifying outcomes of the program, and sharing of information gained from the

evaluation of the program.[21] It will also ensure that a proper description of the program is included by assessing components of the program's statement of need, target audience, outcomes/goals, activities, outputs, resources, context, and relationship between activities implemented and the resulting outcomes.[21] This evaluation framework from the CDC will allow for identification of opportunities to re-assess the program's health behavior goals and how to best implement interventions accordingly in an effective and efficacious manner.

Conclusion

This health promotion community-based program is necessary for children with CP to encourage lasting health behavior change, specifically for increasing independence with participation in physical activity and positive nutritional habits. Evidence-based parameters presented in this proposal were created specific to those with CP and are therefore very applicable and clinically relevant.[6] Not only will this program help increase physical activity levels in these kids, but it will also increase their participation in social interactions, which is pertinent to overall quality of life. This program is set apart from others because it uses the social ecological model and social cognitive theory framework to identify barriers at different levels and implement strategies to address such in a way that increases the child and caregiver's level of self-efficacy and motivation to further encourage long-term change after the program has ended.[11,13] By providing the interventions presented in this proposal, we will be providing children with CP the unique opportunity to take control of their bodies, become more independent with their functional mobility, and enjoy participating in physical activity. Furthermore, the interventions in this program and the education provided to

caregivers throughout will help to mitigate the development of secondary chronic conditions and thus decrease overall healthcare costs.[3,8] Therefore, it is necessary that this program begin as soon as possible so that we can give each child with CP this awesome opportunity to be the best versions of themselves. Thank you!

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